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The “PMLD ambiguity”: articulating the lifeworlds of children with profound and multiple learning difficulties, paper presented at the Nordic Network on Disability Research (NNDR) 11th Annual Conference, Reykjavík, Iceland (28.05.2011)

Abstract:

Profound and multiple learning difficulties, or “PMLD”, is a label given to children in the United Kingdom who are said to be affected by the severest of impairments to consciousness and cognition stemming from neuro-developmental disorders. These impairments are deemed to be so extensive that children with PMLD are described as lacking in explicit awareness of themselves, others, and the surrounding world. The severity of such impairments typically precludes children with PMLD from participating in mainstream education. Instead, best educational practice is said to consist of segregated and controlled environments with intense, one-to-one input from members of staff trained in specialist intervention methodologies.

The purpose of this paper is to present a project that broke away from conventional (psychological) theory, (positivist) research methodologies, and (special) educational practices found in the PMLD field in order to develop new understandings and experiences of children with PMLD. The project explored the opportunities for engagement that non-traditional (i.e. “inclusive”) learning environments present for children with PMLD, and the kind of growth and learning that can emerge in relation to such environments. Exploration of such engagement was conducted through the application of an interpretivist-participatory methodology that was sensitive to idiosyncratic forms of experience and comportment. A critical phenomenological approach (Maurice Merleau-Ponty 1908-1961) was utilized to analyze differences in experiences and comportment in relation to different learning environments. What becomes apparent through the juxtaposition of alternative theoretical, methodological and contextual approaches is that children with PMLD engage with and experience their environments in ways more complex than existing conceptual frameworks capture. Implications of this complexity for theory, research and practice are discussed.

The work presented in this paper is based on Ben’s doctoral thesis of the same title (University of Exeter 2010: supervised by Dr. Phil Bayliss (Exeter), Dr. Debbie Watson (Bristol), and examined by Prof. Dan Goodley (MMU) and Dr. Deborah Osberg (Exeter)).

The paper includes draft material written for the forthcoming book:

Simmons, B.R. and Watson, D. L. (in preparation – 2013) {working title} *The “PMLD ambiguity”: Resisting objectification and articulating the life-worlds of children with profound and multiple learning difficulties*, London: Karnac Books

Introduction

Profound and multiple learning difficulties, or “PMLD”, is a label given to children who are said to experience the severest of cognitive impairments which stem from neurodevelopmental disorders (MDRT Oxfordshire 2001). The abilities of such children are often compared to those of the neonate or infant insofar as children with PMLD are described as operating at the pre-verbal stages of development (i.e. the earliest stages of development which infants are said to pass through during their first year of life) (Burford 1988; Carnaby 2004, Coupe O’Kane and Goldbart 1998, Nind & Hewett 1994; 2001, PMLD Network 2001, Ware 1994; 2003). Consequently, a range of “pre-” descriptors are used in the PMLD literature to indicate that such children typically fail to reach particular developmental milestones associated with later infancy. For example, children with PMLD are understood as being pre-volitional (they lack agency and cannot move with intent) (Logan et al. 2001); pre-contingency aware (they do not show awareness of cause-effect relationships) (Ware 1994; 2003); pre-intersubjective (they do not represent other people as subjects “like me”, and cannot differentiate between subject and object); pre-communicative (they are pre-symbolic and cannot intentionally convey meaning to others) (Goldbart 1994, Coupe O’Kane and Goldbart 1998); stereotypic in behaviour (they display reflexive, non-volitional behaviour) (Tang et al. 2003); and who are at high risk of living in a world of confusion (Cartwright and Wind-Cowie 2005, Ouvry 1987). In addition to profoundly delayed cognitive development, children with PMLD are also said to be prone to a range of other difficulties including physical impairments, sensory impairments, mental illness, complex medical conditions, and limited life expectancies (Lacey 1998, MDRT Oxfordshire 2001, PMLD Network 2001, WHO 1992). Against this backdrop, children with PMLD are described as being highly dependent on others for the most rudimentary care needs and are deemed to require a lifetime of support (Carnaby & Cambridge 2002, Logan et al. 2005).

In recent years the United Kingdom has witnessed a rise in children with special educational needs and disabilities attending mainstream schools – learners who have traditionally been educated in segregated, specialist schools and units. The impetus for such change has largely come from legislation in the form of the Special Educational Needs and Disability Act (SENDA) (OPSI 2001). SENDA has enshrined children’s access to mainstream provision and made the refusal of access on the grounds of a child’s impairments difficult. However, the recent House of Commons Select Committee on Education and Skills report (2006) on special educational needs has supported the general view that inclusive education may only go so far and that full-time mainstream placements for some children are unrealistic. Similarly, Baroness Warnock (2005) has recently challenged the extent to which inclusion can be achieved for all and has championed a future and ongoing role for special schools. The views of the House of Commons Select Committee (2006) and of Baroness Warnock (2005) are continuous with the Special Educational Needs Code of Practice (SENCOP) (DfES 2001). SENCOP (DfES 2001) falls into a familiar governmental policy pattern of emphasising the need for inclusive education for most children whilst reinforcing the segregation of a selected few (Croll and Moses 2000). Specifically, SENCOP (2001) describes how local education authorities must comply with parents’ preference of school unless:

“[...] the school is unsuitable to the child’s age, ability, aptitude or special educational needs, or the placement would be incompatible with the efficient education of the other children with whom the child would be educated, or with the efficient use of resources” (DfES 2001, p.107).

Children with PMLD make up part of the group for which inclusive education is deemed unsuitable and unrealistic. It is argued that such children do not have the cognitive capacity to meaningfully engage with standard learning environments; that mainstream teachers lack the knowledge and skills required to support the development of children with PMLD; and that only special schools

house the appropriate infrastructure and resources that children with PMLD require (Ainscow and Haile-Giorgis 1998, Chesley and Calaluze 1997, Foreman et al. 2004, Ouvry 1987). Instead of being included within mainstream schools, a commonly proposed model for children with PMLD is one of “inclusion” in a mixed-ability class within existing special school provision (as opposed to being placed in a separate special care unit attached to a special school) (Bayliss & Pratchett 2004, Pratchett 2005, Simmons and Bayliss 2007).

The Study¹

The context for the discussion in this paper revolves around an inclusive education research project involving a young boy with PMLD called “Sam”. The project aimed to illuminate the ways in which mainstream education can benefit children who are traditionally educated in special schools. Specifically, the aim of the project was to further our understanding of peer engagement for Sam. For example, we explored whether alternative educational contexts offered qualitatively different opportunities for peer engagement and how these differences could lead to new learning opportunities. For over three years Sam spent one day a week at his local mainstream primary school, and for the rest of the week attended a special care class in a neighbouring city’s special school.

The research methodology was interpretivist and consisted of three inter-linked elements. This is not the place to go into great detail, but further information related to the methodology can be found elsewhere (see Bayliss, 2004; Bayliss and Simmons, 2005; Simmons and Bayliss, 2005). To summarise, firstly a series of semi-structured interviews took place in order to gather the views of significant others (parents, teachers, teaching assistants etc) who knew Sam well in order to grasp interpretations of others and direct initial observations. Second, extended periods of participatory observations were undertaken where a researcher effectively acted as a teaching assistant for Sam once a week in his special school and once a week in his mainstream school. Finally, periods of non-participatory observation were undertaken. It was during these moments that most data was accrued through vignette writing and it is this data which will be discussed shortly. The production of vignettes essentially involved writing in great depth about small events in Sam’s school life, particularly where opportunities for social interaction emerged. Dozens of vignettes were recorded each day both in Sam’s mainstream and special school settings over the space of a year. The quantity and richness of the vignettes allowed the researchers to submerge themselves in the data in order to look for common themes.

Sam’s level of social engagement varied significantly depending on which school he attended and which type of communication partner was accessible to him. In his special school, Sam’s main communication partners were classroom staff and school therapists who supported Sam during lessons and therapy-based sessions. Sam was happy with the adults in his special school, although things were done to Sam by adults (e.g. personal care, therapy-based sessions, sensory stimulation etc) which he clearly enjoyed.

It was extremely rare to see Sam interacting with his special school peers. When opportunities did arise (i.e. when the children were located close to Sam), Sam did not attempt to initiate interaction or respond to potential initiations from other peers. The general opinion of the classroom staff was that Sam was unable to recognise the subtle communicative abilities of his peers and as such he was largely passive and distant around them. However, in his mainstream school, Sam’s communication

¹ The outline of this study is taken from: Simmons, B.R., Blackmore, T.D., and Bayliss, P.D. (2008) Postmodern synergistic knowledge creation: extending the boundaries of disability studies, in ***Disability and Society*** **23** (7), pp. 733-745

partners consisted of classroom assistants and peers, and he was incredibly socially active. Sam reached out to other children very regularly and engaged with others. Instances of Sam interacting with adults were recorded. However, Sam reached out to and engaged with his mainstream peers much more than he did with the adults from either schools. During the first two terms Sam often attempted to initiate interaction by making eye contact, grabbing other children (their arms, legs, hair etc), leaning on them (especially during carpet time) or by simply holding on to them. Reciprocal peer-engagement was often observed, with Sam and his peers mimicking one another and waiting in anticipation for each other's response and often giggling together. Peers often attempted to initiate interaction with Sam by talking to him, holding his hand and sharing items with him (i.e. their toys). Sam responded back enthusiastically.

In the third term, Sam's attempts to interact with his mainstream peers became more 'socially acceptable'. He was much more gentle (e.g. he pulled the other children's hair much less), gave children hugs (rather than grabbing and firmly holding onto them), made more eye contact and for longer periods of time, and stroked or placed his hands on others if he wanted attention. Sam began behaving in the way that other children were encouraged to behave towards him, showing an increased awareness of socially desirable communication skills. By the end of the term more children were approaching Sam and those that were shy of him in the first term became increasingly confident and engaged with him. The children provided a wealth of opportunities for Sam to communicate with others and practice his communication skills – a task he embarked on enthusiastically.

There was also a marked increase in the frequency and quality of Sam's engagement with his special school peers in the third term indicating a transference of communication skills. Sam exhibited some of his mainstream communicative behaviours in his special school, i.e. he started to crawl over to his peers, hug and gently stroke them. On several occasions his peers indicated their pleasure in Sam's affection by giggling, hugging him back or indicating that they wanted more in their own idiosyncratic ways.

Despite Sam's increased social engagement in his special school, the amount and duration of mainstream interactions was much greater. Further, the quality of these mainstream interactions was markedly different with many examples of emerging behaviour involving interactions with people with objects. Sam showed an increased interest in his peers' involvement with objects. When a peer ceased using an object, Sam would often pick up the item and explore it himself (visually, orally and/or kinaesthetically with his hands) and sometimes attempted to interact with the peer after his exploration of the object.

Extended Discussion

This research project (above) has been reported in order to provide a site for assessing the extent to which the different theoretical perspectives (behaviourist psychology, cognitive psychology, and phenomenology) make intelligible Sam's behaviour. Such analysis tests the usefulness of existing and alternative perspectives, which in turn provides material for discussion in the concluding chapter regarding the efficacy of dominant (behaviourist/cognitive) and alternative (phenomenological) approaches to thinking about PMLD. With this in mind, I now present the findings of the research and discuss the findings in relation to the different perspectives.

Switch-based activities

Many of Sam's planned learning opportunities in his special school revolved around the use of micro-switches. These switch-based activities resembled those described in the behaviourist-oriented PMLD literature as described in Chapter 2. A brief summary of the relevant points discussed in Chapter 2 should give context to Sam's switch-based learning opportunities and aid analysis of vignettes.

Behaviourism construes learning as conditioning. Conditioning has two forms: classical (Pavlovian) and operant (Skinnerian). Classical conditioning involves the pairing of an unconditioned stimulus with a neutral stimulus resulting in the neutral stimulus becoming a conditioned stimulus. A conditioned stimulus is a stimulus that has acquired the same behaviour-eliciting powers as the unconditioned stimulus. By contrast, operant conditioning involves increasing the likelihood of a particular behaviour reoccurring through positive reinforcement. The operation through which operant conditioning occurs is the presentation of a reinforcer (stimulus) contingent upon the organism behaving in a particular way. Both classical conditioning theory and operant conditioning theory understand behaviour as reflexive (i.e. non-volitional) and both theories rely on a notion of linear dependence or constancy between stimulus and response (Baars 1986, Gregory 1986, Reber 1995, Skinner 1986).

The behaviourist principles of learning are extended in the PMLD literature. The PMLD child is still understood as a reflexive organism, but the repeated occurrence of stimulus-response constancy is said to support the growth of contingency awareness (knowledge of cause-effect relations), understood as a pre-requisite for volitional action and communicative intent. The use of the terms "awareness", "knowledge", and "preference" in the PMLD literature marks a genuine departure from the original behaviourist conception of the organism as a mindless entity.

Behaviourist-oriented switch-based training programs are typically operant in nature and aim to either establish new switch-press behaviour or evoke a rise in frequency of established behaviour through the presentation of preferred stimuli contingent upon switch-pressing. These programs typically involve trying to encourage a PMLD participant to execute switch-press behaviour through some form of prompting, such as verbal prompts (e.g. "Press the switch.") or physical prompts (e.g. where the prompter takes the hand of the PMLD participant and places it on the switch). The switch-press behaviour results in the presentation of stimuli. It is hoped that this process of prompting will support the development of contingency awareness (knowledge of cause-effect relations) insofar as the PMLD participant learns that the stimuli are contingent upon switch-press behaviour. If this awareness has been established, and if the stimuli are desired, then independent switch-press behaviour will be high in frequency/duration without the need for prompts. Stimuli which are correlated with high frequency/duration switch-press behaviour are defined as reinforcers, insofar as they are deemed to strengthen the likelihood of switch-press behaviour (Lancioni et al. 2002, Logan et al. 2001, Saunders et al. 2003).

Research regarding the efficacy of switch-based training programs aimed at developing contingency awareness and/or switch-press behaviour in people with PMLD has reported mixed success rates (Ivancic and Bailey 1996, Lancioni et al. 2001, Logan et al. 2001, Reid et al. 1991, Saunders et al. 2003). Reasons given for mixed results include difficulties in identifying preferred stimuli to act as reinforcers (Green et al. 1988; 1991; 2000, Ivancic and Bailey 1996, Logan et al. 2001, Pace et al. 1985, Reid et al. 1999, Wacker et al. 1985; 1988), and problems with mediating behaviour states (Guess et al. 1993, Helm and Simeonsson 1989, Wolff 1959). Contemporary research has explored the relation between behaviour state, stimuli preference and micro-switch usage in order to discover optimal learning conditions (Lancioni et al. 2002, Murphy et al. 2004, Mellstrom et al.

2005). Within this research, behaviour states are understood as variables which stand between operant behaviour and contingent stimuli and mediate the probability of switch-press behaviour. Where this is the case, the identification and manipulation of environmental events which influence state conditions are of value to those wishing to alter PMLD behaviour. However, to date, behaviourist researchers have found no generalisable relationship between state behaviour, environment, and micro-switch usage. Each project has found only idiosyncratic relationships between the variables which relate on an individual basis, rather than a trans-PMLD basis. The only exception to this idiosyncrasy is the novel investigation by Foreman et al. (2004) who explored the relationship between behaviour states and social milieu. All PMLD participants observed in mainstream classrooms were said to have spent more time in desirable behaviour states (awake, happy, active, alert etc) and participated more in some form of social interaction than their matched PMLD peers in segregated classrooms. However, no consideration was given to the extent which social milieus effect switch-press activity.

The vignette analysis below compliments and extends Foreman et al.'s (2004) conclusion by exploring the relation between Sam's behaviour state, his switch-press activities and his educational setting. The research found that Sam's range of behaviours towards switches was contingent upon the context in which his switch-based activities occurred. The following two vignettes demonstrate the way Sam usually responded to switch-based learning in his segregated setting. In the first, Sam is placed in front of a computer. The computer software is activated with a press of the switch. Sam passes from Self-Active-Happy when by himself on the carpet (gargling saliva, shaking his head, vocalising) to Passive-Unhappy (his "floppy" body is a form of resistance), to Self-Active-Unhappy (slapping himself, pinching the back of his neck, pulling his hair etc):

Vignette 1: Sam with switch-activated computer program in his special school, adult support – Passive-Unhappy moving to Self-Active-Unhappy

"Sam is sat on the carpet. His head is tilted back as if he is looking up at the ceiling, but his eyes are rolled back. He gargles and shakes his head left and right repeatedly whilst vocalising ("...aaaaah aaaaah uuuuuh aaaaah..."). An LSA² walks over to him, puts her hands under his armpits, picks him up, and carries him a short distance to his wooden chair on wheels. She places him in the chair, straps him (seatbelt around his waist, feet in the stirrups), and clips a tray to the chair. Sam is then wheeled to the computer desk. The LSA connects a switch to the computer, places the switch on Sam's tray, and loads the software. All this time Sam is passive and slouched, almost like a floppy rag-doll. The LSA tests the software to make sure the switch is working. The switch press activates a sample of loud acid house music. The beats are fast and repetitive; the synthesiser riffs are high-pitch and frantic; the vocals are shrill. Animation accompanies the music. Lights flash creating a strobe effect; silhouette figures dance; and "trippy" patterns unfold in the corners of the screen. The LSA has left me to work with Sam. He makes no attempt to press the switch and looks increasingly frustrated, moaning to himself and shakes in his chair (is he trying to get out?), looking everywhere but the screen. I encourage him to press the switch, vocally at first, and then by holding his hand and placing it on the switch. I repeat this several times. The music plays and the graphics flash. Sam becomes aggressive towards himself. He snatches his hand away from me and slaps himself in the face, pulls his hair, pinches the side of his neck and flaps his arms. He repeats in various combinations, over and over. I pat Sam on his back and speak jovially to him, trying to calm him down. He becomes less "self-active". I ask him to press the switch again and avoid touching him. He is not looking at the

² "Learning support assistant" (LSA); also known in the UK as: "classroom assistant" (CA) or "teaching assistant" (TA)

screen. He shakes his head left and right, wiggles in his chair, and slaps his face occasionally. Several minutes pass. I press the switch hoping that he will look at the screen. He only briefly glances at it. He keeps raising his flapping arms and hitting the table with them. He presses the switch with his forearms (but was it accidental?). He repeats the action, but does not hit the switch. Sam is now hitting himself over and over again. His skin is becoming red. Despite holding apart his arms, I can feel him fighting me. Eventually an LSA walks over, removes Sam from the chair and places him on his favourite vibrating rug. He keeps hitting himself and it takes a lot of effort to sooth him”.

From a behaviourist perspective, there is nothing here to suggest that Sam is able to engage in switch-based activities. There is one incident of switch-press behaviour - a single switch-press - but it is unclear whether or not this press was accidental. Is Sam “contingency aware”? Again, there is little in this vignette to say that he is. What counts as evidence of contingency awareness for behaviourism is data demonstrating sustained and repeated pressing (e.g. Green et al. 1988; 1991, Kennedy and Harding 1993, Ivancic and Bailey 1996, Logan et al. 2001, Saunders et al. 2005, etc), something clearly lacking in the above vignette. If switch-press behaviour is the only type of behaviour to be counted as evidence of contingency awareness then Sam is not contingency aware in this (and other) vignettes.

In the behaviourist literature, explanation for the lack of switch-press behaviour includes suggestions of uneducability (Reid et al. 1991), lack of preferred stimuli to act as reinforcers (Green et al. 1988; 1991; 2000, Ivancic and Bailey 1996, Logan et al. 2001, Pace et al. 1985, Reid et al. 1999, Wacker et al. 1985; 1988), and problems with mediating behaviour states (Arthur 2004, Foreman et al. 2004, Guess et al. 1993, Helm and Simeonsson 1989, Wolff 1959). Out of these suggestions, the first is unwarranted. Whilst the above vignette demonstrates no evidence of learning through the switch-based activity, Sam’s self-directed behaviour may be considered as evidence of conditioning derived from “unfortunate contingencies” (Reber 1995, p. 90). The second and third suggestions have some merit. It may be said that Sam is not faced with a preferred stimulus, and as such the computer program does not act as a reinforcer. With regards to the issue of behaviour states, Sam was clearly not in a state conducive to learning. His self-directed behaviours (his hitting) emerged in relation to the switch-based activity – being strapped into a chair and forced to interact with a computer (first, through verbal prompting, and second, through physical encouragement) resulted in a clear decline of behaviour state (he was self-active-happy on the carpet, passive unhappy in his chair to begin with, then self-active unhappy during intervention)

From a behaviourist perspective, Sam’s behaviour would be considered stereotyped (lacking in function) and maladaptive (self-injurious). In Chapter 2, stereotyped and maladaptive behaviours were described as behaviours that fail to provide adequate or appropriate adjustment to the environment (Gregory 1987). Such behaviours were described as repetitive, topographically unvaried, and lacking responsiveness to environmental change. These behaviours were also said to disturb or alarm others and include such things as rocking, hand-flapping, head-weaving, and light-gazing (Murdoch 1997). The reduction of stereotyped behaviour was described as being motivated by three beliefs: (i) stereotypy interferes with learning, (ii) benign behaviours (such as head-banging) may become self injurious, and (iii) responses to individuals with the behaviours will be typically negative (Jones et al. 1995, in Murdoch 1997).

Whilst this single vignette does not demonstrate the topological invariance of Sam’s behaviours (the next two vignettes will serve this purpose), it does show behavioural repetition and a level of unresponsiveness to environmental change (insofar as the behaviours are largely consistent throughout the switch-press activity - though varied in intensity and combination - and continue

after the session (to the extent that it takes a while to sooth Sam afterwards)). And, although this vignette does not demonstrate it, Sam would sometimes become “locked” into his head-hitting, and would repeat the hitting over and over throughout a lesson or session. Despite varying in intensity over the course of the session, the hitting was always present over a prolonged period of time. In the above vignette being discussed, Sam’s behaviour, as stereotyped and maladaptive, may be said to fit into three categories that motivate intervention to prevent the behaviours (according to Jones et al. 1995, in Murdoch 1997): Sam does not press the switch but directs his behaviour towards himself, which may be said to be an inversion of what is required for learning to occur. His slapping, pinching, flapping, and hair-pulling are self-injurious to the extent that red marks appear on his face. Finally, my response to his behaviour was “negative” insofar as I attempted to prevent his self-directed actions, at first in a non-invasive way (jovial speech, back stroking) and later in an invasive way (holding his arms so he is unable to strike himself).

And yet, despite this congruence between Sam’s behaviour and the behaviourist explanation, the behaviour described in the vignette contradicts behaviourism’s most basic premise, i.e. the notion of linear dependence or constancy between stimulus and response. Sam’s “reflex responses” lack one-to-one correspondence with the presentation of the stimulus (be that the presence of the switch or the audio-visual activity of the computer). Sam’s behavioural sequences are varied even though the stimulus remains the same. Behaviourism is unable to give reason to the observation that the same stimuli can provoke different responses. Whilst Sam’s switch presses may be correlated with his self-directed behaviour (in the first instance, I put his hand on the switch, in the second instance, he (accidentally) hits the switch himself), this behaviour is not uniformed but dynamic and varied (despite being clustered under the headings “stereotyped” and “maladaptive”).

This notion of differential responses to the same stimulus is described in vignette 2 (below). This vignette records the daily special school greeting activity in which each child is required to press the switch during a song. The switch press results in a pre-recorded message being emitted: “Good morning!” Sam reacts adversely to the activity.

Vignette 2: Sam with switch-activated greeting in his special school, adult-support – Passive-Unhappy, moving to Self-Active-Unhappy

“Sam has just been strapped to his stander (a wooden frame used to support standing and improve posture). A tray is bolted to the stander and Sam is wheeled to the centre of the classroom where the other children are “standing”. The children form a circle with the teacher in the middle. Sam is looking bored. He licks his bottom lip, rolls his eyes back and shows the whites of his eyes. He shakes his head left and right repeatedly. He stops, curls up his top lip and exposes his teeth, frowns and vocalises unhappy sounds (“...uuuurgh!”) whilst looking up at the ceiling. LSAs place switches on the trays of each child. The teacher sings the “Good morning song” and calls the name of the child who is meant to press the switch at the end of each verse. The switch emits the pre-recorded phrase: “Good morning, everyone!” Sam becomes increasingly impatient. He flaps his arms like a bird. He then starts to slap the side of his face, pinches his neck, and pulls his hair. He pushes the switch off the table and it crashes to the floor. Over time his self-stimulation becomes notably self-injurious, with red marks appearing on his face and neck where he is hitting and pinching himself. An LSA restrains Sam by holding his arms apart whilst talking gently to him. It looks like Sam is fighting the LSA - his movements are centripetal and it is as if Sam is repeatedly trying to hit himself against the will of the LSA. Eventually, it is Sam’s turn to say “good morning” and press his switch. The LSA gently moves both of Sam’s hands over the switch and presses down. The message is played and the teacher enthusiastically wishes Sam

“good morning”. She makes eye contact, smiles then nods and praises Sam. The LSA lets go of Sam’s hands and encourages Sam to hit the switch. Sam pauses. The adults wait in anticipation. Several seconds go by. Sam suddenly pushes the switch off the table and slaps himself in the face”.

Consistent with the previous vignette (vignette 1), Sam’s behaviour during this vignette (vignette 2) is self-directed in a way that may be considered self-injurious. The same type of activity (switch-pressing) is responded to with the same cluster of behaviours directed towards Sam’s own body (predominantly his head). Once again, Sam’s behaviour can be described as maladaptive, a product of “unfortunate contingencies”, lacking in appropriate behaviour state conducive to learning, a product of inappropriate reinforcers etc. And once again, behaviourism is unable to give reason to the observation that the same stimulus (switch-press activity) provokes differential responses (different combinations of maladaptive behaviour: hitting, pinching, fighting the LSA, pushing the switch off the table etc). Now, it may be argued that Sam’s stimulus in vignette 2 (the pre-recorded message) is different to the stimulus in vignette 1 (a computer program), but as will be shown shortly, a pre-recorded voice was the stimulus used in his mainstream school which resulted in the obverse of his special school reactions (Sam was active, happy, frequently pressing the switch etc – more on this shortly). However, even if this were not so, and the challenge that the switch-press resulted in different stimuli remained (thus negating the value of contrasting how the same stimuli could provoke differential reactions), behaviourists would still have to account for the fact that different stimuli resulted in the same behaviour. This is something that the behaviourists cannot do. The same argument against the behaviourist logic is present: the simple constancy between stimulus and response has broken. Behaviourism is unable to make intelligible neither the fact that the same stimulus provoked different reactions, nor can it make intelligible the fact that different stimuli provoked the same reaction. Sam’s behaviour resists being neatly categorised in such a simple way. Inconsistency replaces constancy.

Before attempting to interpret these vignettes from the two remaining perspectives (cognitive psychology and phenomenology), it is worth citing one more vignette which both compliments and contrasts the previous vignettes discussed so far. In this vignette (vignette 3), Sam is presented with a switch which has the pre-recorded message: “Good morning!” (the message is the same as that described in vignette 2). In vignette 3, Sam once again behaves in a way that disturbs the behaviourist stimulus-response relationship, but he does so in a “positive” way (he is happy, excited, active and displaying awareness of switch-press behaviour).

Vignette 3: Sam with switch-activated greeting in his mainstream school, peer-support – Other-Active-Happy, moving to Other-Object-Awareness

“Sam is sat on his artificial grass mat on the carpet for registration. He is in the middle of a group of approximately twenty children. All the children are close to one another, chatting, and filling the room with hubbub. Sam groans and extends his arms and legs in front of him. He then leans back into a group of chatting girls. He giggles and lets them support his weight. The girls giggle and do not move. Although they do not attempt to talk to Sam, they do not move away either and eventually carry on chatting. The teacher calls Sam’s name whilst taking register. Normally at this point Sam would be presented with a switch from his LSA. This does not happen. One of Sam’s neighbours stands up, walks over to a yellow box in the corner near the teacher, pulls out his switch and returns to the carpet. She tells Sam to press his “blue button” and smiles. Sam leans forward. The girl takes Sam’s hand and places it on top of the switch. The switch is activated and emits a pre-recorded “Good morning!” message. Sam repeatedly hits the switch with both hands (he raises his hands, then suddenly slaps the

switch held in front of him, lets his hands fall on his lap, and repeats several times). Sam presses the switch before the recorded message has ended, resulting in the first half of the message being played, over and over. Between each switch-press Sam flaps his arms like a bird whilst smiling and vocalises (“Ooooooh!!!”). He wiggles his legs outstretched in front of him and hits the floor with the back of his heels. He slaps his head with both hands and makes happy sounds. An LSA walks over to Sam and the girl gives the LSA the switch. The LSA crosses Sam’s legs, makes him sit up straight, and walks away”.

In this vignette, Sam is clearly happy and active around his mainstream school peers. He presents as being particularly excited during the switch-based exchange with a peer in which he strikes his “blue button” repeatedly, making “happy noises” (“Ooooooh!!!”) and displaying awareness of how to behave towards switches (switches are for pressing). This behaviour contrasts starkly with his behaviour during switch-based activities in his special school (vignettes 1 and 2). In his special school, Sam’s switch-press behaviour was very limited, whilst being typically adult-supported and resulting in resistance and/or aggression from Sam. Sam’s differential responses to the same stimulus (be that switch-presentation or a pre-recorded “Good morning!” message) extend the point made previously about the breakdown of simple linear dependence. For the behaviourist literature, a stimulus acts as a reinforcer, or it does not. There is no discussion about how the same subject can present as being contingency-aware and not-contingency aware depending on context. Sam’s switch-press behaviour shifts according to where he is and who is supporting him.

This draws attention to the way switch-press behaviour is mediated by behaviour states (Guess et al. 1993, Helm and Simeonsson 1989, Wolff 1959) and the way the behaviour states themselves are mediated by environmental variables. As discussed in Chapter 2, the original behaviour state research found no relationship between behaviour state and environment (Guess et al. 1993). Recent research has explored the relationship between behaviour states and mainstream school environments (Arthur et al. 2004, Foreman et al. 2004). The PMLD participants observed in the mainstream classrooms were said to have spent more time in desirable behaviour states and participated more in some form of social interaction than their matched PMLD peers in segregated classrooms. The original behaviour state research (Guess et al. 1993, Helm and Simeonsson 1989, Wolff 1959) failed to consider whether differential educational environments (mainstream vs. special) or differential peer groups (with vs. without disability) could affect behaviour state.

Sam’s behaviour states complement the findings of Arthur et al. (2004) for (as will be discussed later) Sam’s behaviour state in his mainstream school was predominantly Other-Active-Happy. Contemporary behaviourist research that explores the relation between behaviour state, stimuli preference and switch usage in the hope of discovering optimal learning conditions (e.g. Lancioni et al. 2002, Murphy et al. 2004, Mellstrom et al. 2005) has so far overlooked the way in which mainstream classrooms affect behaviour state. For Sam, there was a clear relation between educational context, behaviour state and switch-press behaviour. As vignette 3 shows, in his mainstream school Sam pressed his switch freely and frequently when on the carpet with his peers. The social milieu had a positive effective on Sam’s behaviour state and switch-press behaviour.

Understanding Sam’s behaviour from a behaviourist perspective has so far yielded mixed results. Sam’s behaviour makes problematic the notion of linear dependence between stimulus and response. His behaviour during switches-based activities is varied and complex and resists being described in terms of simple constancy between reinforcer strength and switch-press behaviour. However, consideration of behaviour states during analysis has allowed fruitful differentiation between levels of alertness in relation to activities and environments.

Behaviourism's failure to make sense of Sam's switch-press behaviour invites interpretation from a different theoretical perspective. In PMLD studies, this alternative perspective is exclusively cognitive psychology. However, cognitive psychology is equally powerless to make intelligible Sam's differential behaviours. To recap, according to the cognitive perspective, behaviours indicative of communicative intent must resemble descriptions of proto-imperative or proto-declarative behaviours (Bates et al. 1975, in Coupe O'Kane and Goldbart 1998). These proto- behaviours, in which a subject co-ordinates the regard of self and other in relation to an object, are described as the earliest form of meaningful communication. Without a capacity for such person-person-object engagement, the subject cannot be considered an intentional communicator (and lacks awareness of other as subject). Proto-imperative behaviour involves an infant using a reach-for-real action as a reach-for-signal. Reach-for-real consists of an infant reaching for something that is within reach in order to get hold of it. Reach-for-signal involves the infant reaching for something that is out of reach. By incorporating looking from the desired object to the adult and then back again into the reach-for-signal, the infant is said to communicate to the adult that s/he wants the object s/he is reaching for, and knows that the adult can obtain it for him/her. The infant is satisfied by the exchange when s/he obtains the desired object. Proto-declarative behaviour is a variation of proto-imperative behaviour. During proto-declarative behaviour the infant directs the attention of the adult toward something of interest in order to share the experience with the adult (as opposed to obtaining an object). During proto-declarative behaviour, an infant may point towards an object and vocalise: "Dah!", whilst shifting his/her gaze between the object and the adult. The infant is satisfied by the exchange when s/he observes the adult's gaze shift from the infant, to the object, and back to the infant again. Typically developing infants are said to engage in proto-imperative and proto-declarative behaviours around 10 months after birth. Coupe O'Kane and Goldbart (1998) suggest that people with PMLD are unlikely to develop these joint attention capacities, and as such will forever remain pre-communicative.

Vignettes 1 and 2 describe Sam interacting (or resisting interacting) with a switch. No proto-imperative or proto-declarative behaviours are described. Thus, from the above perspective, Sam is not intentionally communicating. His behaviour would be labelled "pre-intentional communication" (Coupe O'Kane and Goldbart 1998; Goldbart 1994, Nind and Hewett 1994; 2001, Ware 1994; 2003). Pre-intentional communication is a term given to the act of interpreting the meaning of expressive behaviours, such as crying or laughing. Such expressive behaviours occur without the expressive agent intending to communicate (s/he lacks the ability to do so). Sam's self-directed activity in both vignettes, his act of pushing switches away from his body, and his "fights" with both myself (vignette 1) and his LSA (vignette 2) are not considered forms of intentional communication. Such "negative", resistant or defiant behaviours are not considered to be sources of intended meaning. His movements are clearly expressive, but are pre-symbolic and non-triadic.

Trevarthen and Aitken's (2001) model of infantile intersubjective development is also unable to make sense of Sam's behaviours. As discussed in previous chapters, Trevarthen and Aitken's (2001) cognitive model contrasts to the models used by the PMLD studies community insofar as Trevarthen and Aitken (2001) articulate a view of primary intersubjectivity. Infants are said to be endowed with capacities for sustained social exchanges, motivated by an infant's innate ability to perceive others as subjects rather than objects. However, Trevarthen and Aitken (2001) only describe mutually satisfying social exchanges (person-person, or primary intersubjectivity) or social games involving the mutual coordination of objects (person-person-object, or secondary intersubjectivity, which is similar to the proto-imperative and proto-declarative exchanges described above). Whilst Trevarthen and Aitken's (2001) notion of primary intersubjectivity makes intelligible those behaviours that are non-triadic, primary intersubjectivity is understood solely in terms of face-to-face interaction. The nature of the Sam's behaviour in vignette 1 and vignette 2 is not face-to-face activity. There is no mutual satisfaction, there are no smiles, eye contact, turn-taking, giggles etc. As

such, Trevarthen and Aitken (2001) have nothing to offer. They only provide explanation of the happy (not the unhappy), and of the intimate (not the larger, more aggressive movements described in the first two vignettes). So, once again, Sam's behaviours are lost. They do not "fit" the existing frameworks. Behaviourist and the cognitive approaches cannot account for the behaviours described. They cannot make Sam intelligible.

Vignette 3 describes Sam repeatedly pressing the switch that his peer offered him. During this episode, Sam was clearly happy, excited, and focused on the switch that "spoke" for him (by greeting the class "Good morning!" with each press). The description of the episode captures Sam interacting with an object that a subject is holding, and doing so with zeal. Despite the person-person-object nature of this exchange, Sam's behaviour still evades the term "intentional communication" from the perspective of PMLD studies. Sam does not make eye contact with his peer, point, or reach-for-signal in order to obtain an object. Trevarthen and Aitken's (2001) notion of secondary intersubjectivity may be said to offer room for theorising the interactive event. However, this room exists only because Trevarthen and Aitken (2001) fail to offer anything in the way of a description of what secondary intersubjectivity looks like. If secondary intersubjectivity is to positively afford a greater range of meaningful behaviours than PMLD studies allows for, then there has to be an articulation of something extra. This can be found through a synthesis of Trevarthen and Aitken's (2001) notion of secondary intersubjectivity with aspects of Merleau-Ponty's (2002) phenomenological perspective of being-in-the-world.

Whilst the behaviourist and cognitive perspectives in PMLD studies makes limited sense of the behaviours described in the above vignettes, Merleau-Ponty's (2002) phenomenological perspective allows us to foreground and theorise these behaviours in a much greater way, and does so in a way that can complement Trevarthen and Aitken's (2001) framework.

Chapter 4 discussed Merleau-Ponty's (2002) phenomenology. This discussion articulated Merleau-Ponty's (2002) description of the body as that which is neither an object in-itself (the body-object), nor something to be abstractly represented by a reflective consciousness, a for-itself (the body image). This third position between subject and object is a pre-objective understanding of the body. This bodily dimension is a mode of existence or being-in-the-world in which organisms have a form of bodily intentionality that plays beneath any overt sense of self, any thematic ego. When Merleau-Ponty (2002) characterises the body in terms of "existence", he means that the body is defined by its "projects" (p. 129): my body "appears to me as an attitude directed towards certain existing or possible tasks" (p. 114). Hence, the spatiality of the body is not one of "location" but of "situation". The "here" of the whole body is its "situation in face of its tasks" (p. 115) in which objects offer themselves as "poles of action" (p. 122). The body "surges" towards objects to be grasped (p. 121). These objects are understood as "manipulanda" – objects known in terms of how they can be acted upon, or with (p. 120). The world is "a collection of possible points upon which [...] bodily interaction may operate" (p. 121). Motility, "in its pure state, possesses the basic power of giving a meaning (Sinngebung)" (p. 164). This is essentially what Merleau-Ponty refers to as "motor intentionality" (p. 127): "Consciousness is in the first place not a matter of 'I think that' but of 'I can'" (p. 159).

From Merleau-Ponty's (2002) phenomenological perspective, Sam's differential switch-press behaviour is a result of the way in which the different educational situations are practically signified. Different situations express different possibilities for interaction. For Sam, the stimuli contingent upon switch-press behaviour is not universally important (if it was, he would have behaved enthusiastically towards switch-based activities in each of his settings where the stimuli were consistent, which was not the case). What appears to be important for Sam was firstly his freedom. In his special school Sam was typically strapped into chairs and standers (something captured in

vignette 1 and 2), in his mainstream school he was typically without such constraint (captured in vignette 3). Sam was typically aggressive towards himself during times of constraint, and as such was typically aggressive when in his special school (although self-directed aggression was observed in his mainstream school, but with much less intensity and frequency). Secondly, the social milieu was important for Sam. As will be discussed later, Sam was most active around his mainstream school peers. Since the social milieu was an important factor mediating Sam's switch-press behaviour, the question emerges as to what specifically Sam finds significant in these contexts – how does the social situation relate to motor significance? To reiterate a previous point, Sam's behaviour towards switches is unintelligible from the cognitive perspective. Trevarthen and Aitken's (2001) secondary intersubjectivity (in which two people mutually engage with objects) is somewhat consistent with Coupe O'Kane and Goldbart's (1998) description of intentional communication (borrowed from Bates et al. 1975). Whilst Trevarthen and Aitken (2001) fail to offer any behavioural descriptors of secondary intersubjectivity, Coupe O'Kane and Goldbart (1998) offer behavioural descriptors indicative of proto-declarative or proto-imperative competence. The vignettes above do not conform to the proto-imperative/-declarative descriptors and as such Sam could not be considered to be an intentional communicator. And yet, Sam does engage with the switch when in the presence of peers in his mainstream school. How can we make sense of this? One explanation would be that the behaviours prescribed by PMLD studies as indicative of intentional communication are too narrow. This is not to negate the value of proto-imperative/-declarative behavioural descriptors, but to call for a broader catalogue of behaviours suggestive of intersubjective awareness and communication. Another explanation may be that Sam's behaviour reveals an emergent level of awareness that is more sophisticated than Trevarthen and Aitken's (2001) primary intersubjectivity (person-person interaction) but not as sophisticated as genuine secondary intersubjectivity (person-person-object interaction as proto-imperative/-declarative). This new form of "proto-secondary-intersubjectivity" would explain why, in the presence of his peers, Sam wilfully engages with objects. There is something significant for Sam in this interactive situation, but this significance is not at the level of abstract, symbolic communication (proto-declarative/-imperative). For Merleau-Ponty (2001), being-in-the-world consists of perception and action being linked in the sense that what is perceived is immediately understood as that which can be acted upon. Experience requires or calls for movement. If this view is synthesised with that of Trevarthen and Aitken's (2001) understanding of the emergence of object cognition, then we become one-step closer to theorising Sam's "proto-secondary-intersubjectivity". As discussed previously, Trevarthen and Aitken (2001) argue that infants possess an innate capacity for intersubjective awareness. Further, in contradistinction to the claims of PMLD studies generally (Coupe O'Kane and Goldbart 1998, Nind and Hewett 1994; 2001, Ware 1994; 2003 etc) which grounds itself in theories of other cognitive psychologists (e.g. Bates et al. 1975, Piaget 1962; 1968, Schaffer 1971a; 1971b, 1984 etc), Trevarthen and Aitken (2001) argue that object cognition emerges through early social exchanges, rather than vice-versa. To quote Trevarthen and Aitken (2001):

"[...] the prevailing logic needs to be reversed; that object cognition and rational intelligence in infants, and their perceptual preferences, should be viewed as the outcomes of a process that seeks guidance by person-perception and through communication with equivalent processes, of cognition-with-intention-and-emotion, in other persons" (p. 4).

From the perspective of PMLD studies, children with PMLD are pre-communicative because they are unable to comprehend the objective world (for example, they lack contingency awareness, etc). From Trevarthen and Aitken's (2001) perspective, infants learn about the objective world through social engagement, defined in terms of primary intersubjectivity. If Trevarthen and Aitken (2001) are right, then it makes sense to say that Sam's switch-press behaviour in the presence of peers (and not adults or computer screens) emerged because it was through his peers that the switch was

understood as that which can be acted upon. It was through sharing experiences with his peers that called for Sam's actions toward the switch. For Sam, the social milieu (Trevvarthen and Aitken 2001) in his mainstream school presented as a behavioural setting (Merleau-Ponty 2002), which signified objects as that through which social engagement took place. The adults and peers in Sam's special school context did not present in this way. As will be discussed during analysis of the next group of vignettes, Sam was typically passive around others in his special school. The school was void of motor significance on the scale that was seen in his mainstream school.

Previous discussion considered the role of behaviour states (Guess et al. 1993, Foreman et al. 2004, Arthur 2004) as mediating Sam's engagement with his environments. From the behaviourist perspective, these states are considered to intervene by disturbing the "readiness" of Sam to respond to his environmental stimuli. From Merleau-Ponty's (2002) perspective of being-in-the-world, these states take on new meaning. The behaviour states emerge when Sam finds himself in a situation of significance. Whilst being in a segregated classroom governed by behaviourist principles of learning may be non-stimulating for Sam (vignettes 1 and 2), being around others (especially peers) is meaningful and raises bodily expectations, alertness etc, and primes Sam to engage with his social milieu. The behaviour states work beneath abstract forms of representational consciousness whilst motivating switch-press behaviour. Australian behaviour state research (Foreman et al. 2004, Arthur 2004) indicates that PMLD children are in optimal learning states when in mainstream social milieus. Observations of Sam in this study compliment the Australian research.